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Publication Date

2019

DOI

10.2147/pgpm.s187657

Peer reviewed

Population's perspectives toward biobanks in scientific research: a study from Jordan

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Background: Biobanks (biorepositories) were established to compile collected bio-specimens for future research and usage. The collection/storage of bio-specimens triggers several social, legal, and ethical implications where public attitudes can represent the core measurement/parameter in defining the most acceptable practices and ethical approaches when dealing with biobanks.

Aim: The aim of this study was to explore and understand population's perspectives, expectations, and concerns toward biobanks in Jordan.

Methods: A cross-sectional survey that included closed-ended questions was distributed among Jordanians. A total of 500 participants who are representative of the Jordanian population were included in this study.

Results: There was overwhelming support (>85%) for the establishment of biobanks in Jordan, and most of the participants agreed on the importance of biobanks and samples' donation for promoting medical research. Enthusiasm in biobanking participation was associated with the sociodemographic characteristics of participants including age, educational level, and previous knowledge of biobanks. Moreover, considering sample donation as a religiously good deed appeared to have the strongest positive correlation with willingness to donate bio-specimens for future research. Also, participants' trust in medical and research services, especially the protection of their privacy and confidentiality, was the most critical concern when they decided to participate in biobanks.

Conclusion: Population's attitude toward biobanks in Jordan was positive and promising, and can encourage the future establishment of different biobanks. It is also necessary to take into consideration certain sociodemographic characteristics when discussing specific information with potential biobanks' donors.

Keywords: biorepositories, sample storage, sample donation, sample reuse, ethics

Introduction

The availability of bio-specimens and their corresponding information is a core demand for conducting biomedical researches. In the last century, these specimens or information used to be collected independently for each study. This approach increased the duration, cost, and the effort to conduct clinical studies. Moreover, such limitations sabotage the researchers' ability to conduct large and high-throughput representative studies, either locally or at the international level.^{1,2}

Biobanks, as public biorepositories for global research, were widely developed at the end of the last century (1990) to compile collected de-identified bio-specimens.³ These biobanks were able to provide researchers with a massive genomic and pheno-

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typic database, representative of many people from extensive geographical areas.^{3,4} Recent advances in biomedical technologies and in understanding of the human genome advocate the value of conducting research on stored bio-specimens and their related health information.⁵ Biobanks can help in the progression of medical research and enable performing a number of studies and samples on many complex diseases with the ability of conducting genetic analysis in light of the demographic, environmental, medical, and ethnic records.⁶ Obtaining sufficient and representative samples for genome-wide association studies or screening studies for lethal and disabling conditions/biomarkers, especially in infants, would be impossible without the development of biobanks.^{7–10} Moreover, this knowledge can be clinically translated and can practically help as diagnostic and therapeutic tools in what is recently called “precise or personalized medicine.”^{11,12}

Ultimately, biobanks’ applications are significantly improving the public health sector.

Despite that and due to the evolving nature of biobanks, the collection and storage of bio-specimens triggered several social, legal, and ethical implications.¹³ In general, biobanks amended the general ethical concepts from individualist ethical approaches to public health ethical approaches, where the focus is on overall public values, attitudes, perspectives, and acceptance of any approach. This carried a huge debate and ethical concerns. Among them are privacy and confidentiality of personal information,^{14,15} research autonomy,¹⁶ open consent model, sharing research results or incidental findings with participants,¹⁷ and the possible usage and benefits from these samples when they are used by specific companies to develop products or services.¹⁸ Thereafter, public attitudes toward the idea of biobanks can represent the core measurement/parameter in defining the most acceptable practices and ethical approaches when dealing with biobanks. Nevertheless, biobanks can also be accompanied by multiple concerns, which can be carried out by the individual donors themselves. Unfortunately, the willingness to donate bio-specimens for future research can be affected by these concerns especially in countries where cultural and religious beliefs can affect people’s choices and decisions.¹⁹ Therefore, the perception of biobanks should be clarified and considered carefully for different ethnicities and cultural backgrounds.

Several studies have investigated the participants’ preferences regarding storage/reuse of collected bio-specimens especially with the recent interest in developing biobanks around the world.^{20–25} In November 2011, King Hussein Cancer Center Amman, Jordan announced the establishment of a cancer biobank for Jordan and neighboring countries.²⁶

Deliberation of best practices is necessary to enhance recruitment efforts and public support for such projects. Therefore, the aim of this study was to explore and understand population’s perspectives, expectations, and concerns toward biobanks in Jordan. The current results are expected to help in enhancing recruitment efforts and to establish new policies to promote scientific research while taking into consideration participants’ rights.

Methodology

Study design and study population

This study was approved by our local institutional review board committee at King Abdullah University Hospital under the approval number (34-105-2017). The study consisted of a cross-sectional survey that included closed-ended questions. The distributed questionnaire was written in Arabic. Participants’ attitudes were measured on a 5-point Likert scale with scores ranging from “strongly agree” to “strongly disagree.” The questionnaire was developed in English and was translated to Arabic, and it was pilot tested to ensure that the questions and the language that was used were comprehensible and clear to the participants. It was validated by four experts in bioethics including epidemiologists, statisticians, scientists, and a bioethics philosopher. The questionnaire was modified based on the pilot testing and expert feedback. It was then distributed online using Google forms between May and June 2017. The questionnaire was collected from 500 participants aged ≥ 18 years reflecting the socioeconomic and demographic distribution of Jordanian people. An informed consent form was provided to the participants before they started answering the questionnaire. Participants’ informed consent was obtained by pressing the send button at the end of the questionnaire. No identifying personal information was obtained from the participants.

Questionnaire backbone and main domains

The questionnaire consisted of three major domains: 1) demographic and socioeconomic characteristics; 2) participants previous research experience; and 3) participants perspectives toward participation in biobanks and storage of their samples.

A short paragraph was included before the last two domains to help increase the knowledge of participants in each specific subject, since it was indicated earlier after the pilot testing and from previous studies conducted in Jordan

that a large percentage of participants had no previous research experience and acknowledged that they have no prior knowledge about biobanks.

The following information was provided to the participants before they answered the questions about their previous research experience.

Research is an investigation conducted to discover new facts or to get additional information about a certain disorder; by collecting then conducting experiments on biospecimens such as blood, urine, hair, nails, or body tissue removed after surgery, or by collecting information either from health records or questionnaires.

Scientific research also includes drug response trials in which patients' response to a specific drug or treatment is evaluated.

After finishing this section, participants were asked about their attitudes toward biobanking and bio-specimens' donation for future research. The following paragraph preceded these questions.

Biobank is an organized repository in which donated biospecimens are stored in. The compiled biospecimens are usually linked to the donor's health information and personal information, biobanks support unlimited number of studies, especially genetic research.

Biobanks operate under strict privacy and confidentiality measures to ensure protection of donor's personal identifying information; all personal identifiers are encrypted using codes to make it impossible to identify the identity of the donor. These codes are kept in closed and safe place, only specified personnel can access. Any research team intending to use these samples in research will not have (code) that links samples to identifying personal information.

Statistical analysis

Data were analyzed using the SPSS® software version 21 (IBM Corporation, Armonk, NY, USA) for Windows. Simple descriptive statistics were used to report participants' characteristics, frequencies, and percentages. Cross-tabulation (Pearson's chi-square) was used to assess the relationship between attitudinal statements, demographics, and socioeconomics, participants' earlier knowledge about biobanks, and participants' previous participation in research. The correlations between responses within each statement and the overall willingness to participate in biobanking for future research were assessed by calculating Spearman Rho correlation coefficient.

Results

Demographics and participants' characteristics

Surveys were collected electronically from 500 participants; 24 questionnaires were excluded from the analysis as they were not filled completely. Table 1 shows the demographics and socioeconomic characteristics of the respondents. The study sample had almost equal proportions with respect to gender; females (52%, n=248) and males (48%, n=228). The majority of respondents (59%, n=281) were between 18 and 29 years, and about 19.5% (n=93) were between 30 and 39 years, while 21.5% (n=58) were above 40. These percentages correspond to Jordanians' demographic distribution favoring younger ages. A large proportion of respondents (67%) held an undergraduate degree, while slightly more than a quarter of the respondents held graduate degrees, and around 7% (n=35) had an education level of high school or less.

Participants' previous research experience

Regarding previous research participation (Table 2), around 50% of respondents never participated in research before this study, while 46% participated, and 3.6% of the participants stated that they were offered participation in a research study but refused.

When participants were asked to assess their knowledge about biobanks, 60% of participants estimated their

Table 1 Demographics and socioeconomic characteristics of the study population

Characteristics		Count (n=476)	%
Gender	Female	248	52
	Male	228	48
Age (years)	18–29	281	59.0
	30–39	93	19.5
	40–49	44	9.2
	Over 50	102	21.5
Education level (degree)	High school or less	33	7.0
	Undergraduate	310	67.3
	Graduate	122	25.7
Residence	Village	104	22.3
	City	268	57.5
	Capital	94	20.2
Monthly income (JOD)	<500	207	44.1
	500–1,000	151	32.2
	>1,000	111	23.7

Abbreviation: JOD, Jordanian Dinar.

Table 2 Participants' previous research experience and knowledge

Participants' characteristics		Prior participation in research				Prior knowledge about biobanks			
		Yes	No	Refused	P-value	Low	Medium	High	P-value
Accumulative %		46.4	50	3.6		59.5	35.8	4.7	
Gender	Female	45.1	51.2	3.7	0.781	57.9	36.4	5.8	0.487
	Male	48.2	48.6	3.2		61.3	35.1	3.6	
Age (years)	18–29	41.9	53.4	4.7	0.099	59.4	37.3	3.3	0.138
	30–39	53.8	44.1	2.2		65.2	27.2	7.6	
	Over 40	52.7	46.2	1.1		53.7	40.0	6.3	
Education level (degree)	High school or less	25.0	75.0	0.0	0.002 ^a	82.1	14.3	3.6	0.004 ^a
	Undergraduate	43.7	52.2	4.1		58.1	39.0	2.9	
	Graduate	59.7	37.8	2.5		58.0	32.8	9.2	
Residence	Village	49.0	47.1	3.8	0.867	64.4	31.7	4.0	0.113
	City	45.7	51.7	2.6		59.7	36.9	3.4	
	Capital	46.2	49.5	4.3		53.8	36.6	9.7	
Monthly income (JOD)	<500	41.4	55.7	3.0	0.238	62.7	34.8	2.5	0.181
	500–1,000	50.0	45.3	4.7		58.1	37.2	4.7	
	>1,000	53.7	43.5	2.8		54.1	37.6	8.3	
N=476									

Note: ^aP<0.05.

Abbreviation: JOD, Jordanian Dinar.

knowledge as low, nearly 35% estimated their knowledge as medium, and only 5% estimated their knowledge as high. Further analysis showed significant association between higher level of education with better prior knowledge about biobanks ($\chi^2=15.208$, $P=0.004$) and previous participation in research ($\chi^2=16.719$, $P=0.002$).

Participants' perception toward biobanking and bio-specimens donation for research

Table 3 shows participants' attitudes toward biobanking and bio-specimens donation for future research. There was overwhelming support (>85%) for the establishment of biobanks in Jordan, and most of the participants agreed on the importance of biobanks and sample donation in promoting medical research. This positive view showed strong statistically significant association with higher prior knowledge about biobanks ($\chi^2=19.2$, $P=0.004$). Regarding sample donation for research, 85% of respondents expressed their willingness to donate bio-specimens for biomedical research whereas 79% expressed their willingness to store/reuse these bio-specimens for future research. Similar to the importance of biobanks and samples' donation, there was a statistically

significant association between participants' agreement with the latter statement "store/reuse of bio-specimens for future research" and high prior knowledge about biobanks ($\chi^2=18.1$, $P=0.02$).

The overall percentage of participants' attitudes toward participation in biobanking/sample donation for future research is shown in Figure 1. The most agreed on statements, which would positively affect respondents' willingness to participate in research, were presence of strong privacy and confidentiality measures (97%), contribution to the development of society and knowledge, and helping individuals suffering from a certain illness (95%). This was followed by considering sample donation as a religiously good deed and it was agreed on by about three-quarters of the participants. There was no statistically significant association between the previous statements and demographics. On the other hand, the least agreed on statements were participation to get material returns (22%) and participation to get free medical tests or medications (34%). Further analysis showed no significant association between the latter statement and the income of participants; however, it was statistically significant with lower education level ($\chi^2=30.058$, $P<0.01$), with no previous research participation ($\chi^2=16.396$, $P=0.03$), and being a female ($\chi^2=10.058$,

Table 3 Participants attitudes toward sample donation and biobanking

		Biobanks have an important role in promoting medical research	You might donate bio-specimens for research	Have you been asked to store donated bio-specimens for future research	I support the establishment of biobanks
Accumulative %		87.1	84.9	79	90
Gender	Female	90.2	86.9	83.2	92.2
	Male	83.4	83.4	76.1	88.8
Age (years)	18–29	92.2	83.4	80.2	89.6
	30–39	82.1	84.9	76.3	88.1
	Over 40	87.1	90.4	82	95.7
Education level (degree)	High school	85.7	85.7	75	85.8
	Undergraduate	89	84.9	81.3	90.1
	Graduate	82.3	85.6	76.6	92.5
Residence	Village	79.8	82.7	73.8	87.3
	City	87.9	85.7	81.4	92.6
	Capital	92.6	86.2	82.6	89.2
Income (JOD)	<500	86.7	86.2	81.6	90.1
	500–1,000	85.3	82.7	80	89.3
	>1,000	90.7	86.1	76.1	92.7
Prior participation in research	Yes	84.8	86.2	79.3	91.7
	No	89.2	85.7	80.1	90.4
	Refused	87.6	62.6	81.3	81.3
Knowledge of biobanks	Low	85	83.2	77.4	89.8
	Medium	89.2	87.3	82.6	91.5
	High	95.4**	90.9	85.7*	90.5

Note: * $\chi^2=19.2$, $P=0.004$; ** $\chi^2=18.1$, $P=0.02$.

Abbreviation: JOD, Jordanian Dinar.

$P=0.03$). Trust was also among the most agreed on statements that affected participation positively, and it showed strong statistically significant association with participants over 40 years.

When participants were asked about their concerns over participation in biobanking (Figure 2), fear of sample exploitation by governmental and commercial bodies was the most agreed on statement (70%). This was followed by fear of using samples in religiously prohibited research (>65%). The latter statements showed statistically significant association with younger participants ($\chi^2=10.058$, $P=0.03$), followed by factors related to privacy and confidentiality. Fear of the negative effects of research on privacy and confidentiality was agreed on by 45% of participants. This showed statistically significant association with higher education level

($\chi^2=23.525$, $P=0.024$) and previous refusal to participate in research ($\chi^2=16.396$, $P=0.03$), followed by fear of disclosure of stigmatizing information which was agreed on by 45% of participants (Figure 2). High prior knowledge of biobanks showed statistically significant association with the latter statement ($\chi^2=10.058$, $P=0.03$).

Correlation of several factors with willingness to donate bio-specimens for reuse in future research

To determine which factors correlate with the participants willingness to store their donated bio-specimens for future research (participation in biobanking) and to determine the type of relationship impact on participants' decision (as

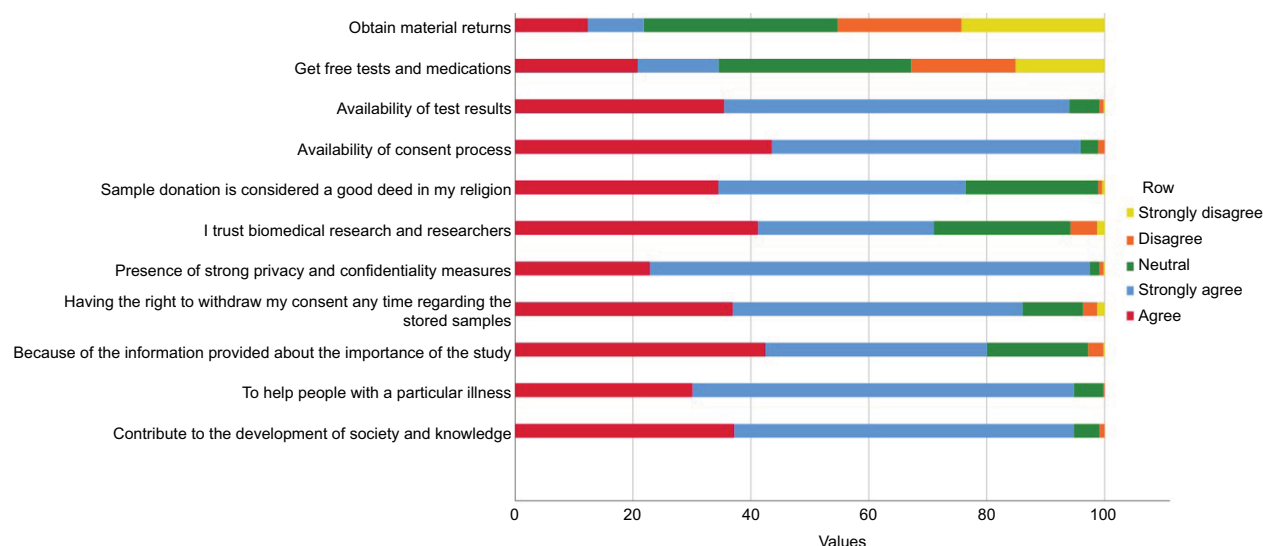


Figure 1 Jordanians' attitudes toward participation in biobanking: encouraging factors.

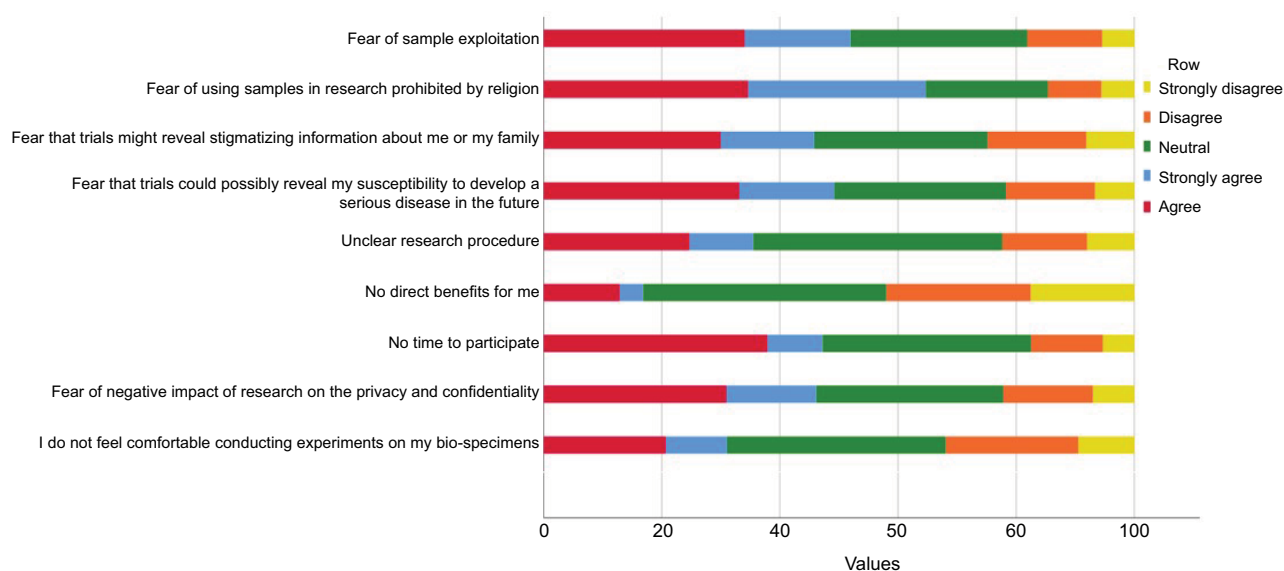


Figure 2 Jordanians' attitudes and fears toward participation in biobanking: discouraging factors.

having a positive or negative effect), Spearman's Rho correlation coefficient was used upon ranking positively influential statements (Table 4). Considering sample donation as a good deed in religion had the strongest correlation with willingness to store/reuse donated specimens for future research ($r_s=0.474$, $P<0.001$). This was followed by high level of trust toward biomedical research and researchers ($r_s=0.465$, $P<0.001$), the availability of the consent process ($r_s=0.352$,

$P<0.001$), and the willingness to help individuals suffering from an illness ($r_s=0.325$, $P<0.001$). Moreover, willingness to donate bio-specimens for storage/reuse for future research also had positive but weak statistically significant correlation with obtaining material returns ($r_s=0.162$, $P<0.01$), availability of test results ($r_s=0.165$, $P<0.01$), obtaining free tests/medication ($r_s=0.147$, $P<0.01$), and with the presence of strong measures to ensure privacy and confidentiality

Table 4 Correlation of different factors with the willingness of participants to donate bio-specimens for future research

Factors that positively correlate with willingness to donate samples for storage/reuse in future research [#]	r_s (p)	Factors that negatively correlate with willingness to donate samples for storage/reuse in future research [#]	r_s (p)
Sample donation is considered a good deed in your religion	0.474**	I do not feel comfortable conducting experiments on me or on samples that belong to me	-0.198**
Trust biomedical research and researchers	0.465**	High prior knowledge about biobank	0.126**
Biobanks have an important role in promoting medical research	0.411**	Fear of the negative effects on my privacy and confidentiality	0.124*
Help people suffering from an illness	0.325**	No direct benefits form participation	-0.117*
Availability of consent process	0.352**	Research procedure is unclear	-0.106*
Because of the information provided about the importance of the study	0.324**	Factors that do not correlate with willingness to donate samples for storage/reuse in future research	r_s (p)
Contribute to the development of society and knowledge	0.292**	I do not have time to participate	0.011 (0.817)
Obtain material returns for participation	0.162**	Future studies could reveal stigmatizing information	0.059 (0.206)
Availability of test result	0.156*	Fear of using samples in religiously prohibited research	0.063 (0.178)
To get free tests and medications	0.147*	Fear of sample exploitation by commercial and governmental bodies	0.007 0.841
Measures to ensure privacy and confidentiality	0.134*		

Notes: [#]Statistically significant result. *Statistically significant result at $P<0.01$. **Statistically significant result at $P<0.001$.

($r_s=0.134$, $P<0.01$). Agreement to donate samples for storage/reuse for future research also had weak statistically significant negative correlation with the participant not being comfortable conducting experiments on his samples ($r_s=-0.198$, $P<0.001$), high prior knowledge about biobank ($r_s=-0.126$, $P<0.001$), fear of negative effects on participant's privacy and confidentiality ($r_s=-0.124$, $P<0.01$), and unclear research procedure for participants.

Discussion

The current study provides some insight on Jordanians' perception toward an important aspect for advancing biomedical research, which is the willingness to donate bio-specimens for future research. Current results are representative of Jordan's general population and were not restricted to specific research subgroups or patients. Moreover, the results may be of importance to neighboring countries due to sharing of some of the cultural and social backgrounds.

As demonstrated by the current results, Jordanians have a positive view toward research even though they did not seem very knowledgeable about biobanks before the start of the study. About 60% of participants estimated their knowledge as low and about half of them had never participated in research before. However, 87% of participants acknowledged the importance of biobanks in promoting medical research

and 90% supported the establishment of such projects in Jordan.

When participants were asked if they would donate their bio-specimens for future research, 79% of them agreed or strongly agreed with this idea. It is noteworthy that widespread willingness similar to that recorded in the current study was observed in previous studies performed in the USA,²⁰ UK,²¹ Sweden,²² and Uganda.²³ In those studies, >80% of the respondents were willing to donate their bio-specimens for future research. On the other hand, this study showed either lower or higher percentages of agreement to donate bio-specimens for future research in comparison with other countries. For instance, in the UAE, >95% of respondents were willing to donate bio-specimens for future research.²⁴ In Egypt,²⁵ only 63% of participants were enthusiastic about donating bio-specimens for future research. Interestingly, those differences do exist even though both UAE and Egypt are countries with relatively similar cultural, traditional, and religious backgrounds to Jordan. This can indicate to the differences in research and medical environments and previous population experiences among those countries. This may also reflect differences in studies' designs among different research groups. In Jordan, perspectives toward donating bio-specimens for biobanks were previously reported among multiple sclerosis and dental patients.^{27,28} Only one study has

previously targeted the Jordanian general population.^{29,30} Notably, the current study showed that higher percentages of Jordanian public are willing to donate bio-specimens for future research (79% vs 63.8%).^{29,30} This might be related to the sufficiency of the information provided to the participants before they answered the corresponding questions. We believe that careful and documented explanations of biobanking acted as a modulator and shifted views in favor of biobanks by providing participants with assurances that increased their awareness and reduced their concerns over participation. This complies with the current hypothesis that education has a critical role in promoting public participation in biobanking.³¹ Moreover, our survey focused only on biobanks without distracting the interviewer or the interviewee with other aspects of medical research and without restricting their answers to cancer research.

When participants were asked if they would donate their bio-specimens for research, around 86% agreed/strongly agreed with the statement. Whereas when participants were asked if they would allow storage and reuse of the donated samples, almost 10% of them changed their opinion. This small reluctance in participation could be related to reasons other than sample donation itself. "I do not feel comfortable conducting experiments on my samples and fear of the negative effects on my privacy and confidentiality" showed the highest levels of negative correlation with willingness to provide bio-specimens for future research. In accordance with that, 97% of participants agreed on the importance of maintaining privacy and confidentiality of donors and unfortunately 45% considered fear of breaching the privacy and confidentiality of donors as a concern for participation in biobanking. This fear was associated particularly with older participants and those who previously refused to participate in research, thereafter, showed a weak negative correlation with the willingness to donate bio-specimens for future research. Based on those results, it seems that privacy concerns did not completely deter participants from taking part in research. However, it could be one of many factors that participants may take into consideration when deciding to participate in biobanking.

It is also interesting to note that higher knowledge of biobanks correlated negatively with the willingness to donate bio-specimens for future research. This contradicts the results obtained by Goddard et al in 2009,³² where participants who had higher knowledge about biobanks were more willing to participate in biobank-related activities. To explain these results, it is possible that participants with high knowledge

of biobanks can determine potential pitfalls of biobanking on autonomy, privacy, and confidentiality of participants and this could, in turn, deter them from sample donation. In agreement with that, fear of sample exploitation and fear of using collected samples in religiously prohibited research were among the most agreed on concerns over participation in research, particularly among younger participants. However, we found no statistically significant correlation between the latter concerns and willingness to donate bio-specimens for future research/biobanks. On the other hand, considering sample donation as a religiously good deed appeared to have the strongest positive correlation with willingness to donate bio-specimens for future research. This result disagreed with other previous studies where the perception of respondents to research was negatively affected by presumed religious beliefs.³²

Another interesting aspect, when comparing between different studies, is the importance given to the effect of trust on enthusiasm to participate in biobanking. In this study, trust appeared to act as a major influencing factor, which can affect the aforementioned aspects of research. Trust is an integral part for advancement of biomedical research.^{5,34,35} Numerous studies reported a positive correlation between the level of trust and individuals' readiness to donate bio-specimens.^{29,35,36}

Limitations

The response rate in this study cannot be calculated given that the recruitment method depended on social media network to cover a diverse population in the community and to collect responses from different geographical areas in Jordan. Also, we relied on participants' self-reported attitudes and hypothetical scenarios, rather than actual behaviors. The design of the current study may have possibly excluded some valid participants who are less educated, elderly, rural, and others who are less likely to be engaged with social media. However, unlike other countries and according to unofficial websites, in Jordan >70% of the population have social media accounts. Moreover, it is worth mentioning that according to the Jordanian culture, opinions of the educated and young family members are well respected by the other members (elderly and less educated) and may have high influence on their choices in many aspects of their lives including their decision on donating bio-specimens for biobanks.

Given that this is an online survey provided to the general population, the true responses and the accuracy of the reported information cannot be verified.

Conclusion

The enthusiasm to participate in biobanking was associated with sociodemographic characteristics of participants particularly with age, educational level, and previous knowledge of biobanks. Trust in medical and research services, especially protection of participants' privacy and confidentiality, is critical when there is support to participate in biobanks. Accordingly, it is necessary to take into consideration those factors that emerged from our study when discussing specific information with potential biobanks' donors. The population attitude toward biobanks in Jordan was positive and promising, and can encourage the future establishment of different biobanks.

Acknowledgments

This project was carried out as part of "The Research Ethics Education Program in Jordan" and has been supported by NIH (grant number 1R25TW010026-01). The authors thank the Deanship of Research at Jordan University of Science and Technology for their support.

Disclosure

The authors report no conflicts of interest in this work.

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